

Parkinson's Employment Study Newsletter

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Shirley Ryan
Abilitylab®

Hello PIECE Study Participants!

Parkinson's Disease: Intervening Early Concerning Employment (PIECE)

We sincerely thank you for your ongoing participation in our study looking at job retention and employment for people with Parkinson's disease (PD).

Our objectives are to track which clinical employment support services are accessed and to monitor employment changes over time in people with PD.

Your partnership is crucial to helping us understand the reality of employment barriers for people with PD, and how we can intervene to address these challenges.



Miriam Rafferty
Principal Investigator



Kurt Johnson
Co-Principal Investigator



Elizabeth Munsell
Postdoctoral Fellow



Jessica Huerta
Voc Rehab Counselor



Emily Zivin
Social Worker



Pam Capraro
Voc Rehab Counselor



Paulo Aco
Project Coordinator



Kevin Smaller
Project Coordinator



Nnaemezie Ezeife
Research Assistant



Sydney Achler
Project Coordinator

Research Team Updates

Paulo Aco, MS: Paulo is a new Project Coordinator that recently graduated with a Master of Science in Kinesiology from the University of Illinois-Chicago.

Elizabeth Munsell, PhD, OTR/L: Elizabeth will be transitioning to a new position as the Research Director in Occupational Therapy for Pearson Assessments.

Sydney Achler, MPH: Previous Project Coordinator Sydney has moved on to be the Evaluation and Impact Manager for Cubs Charities.

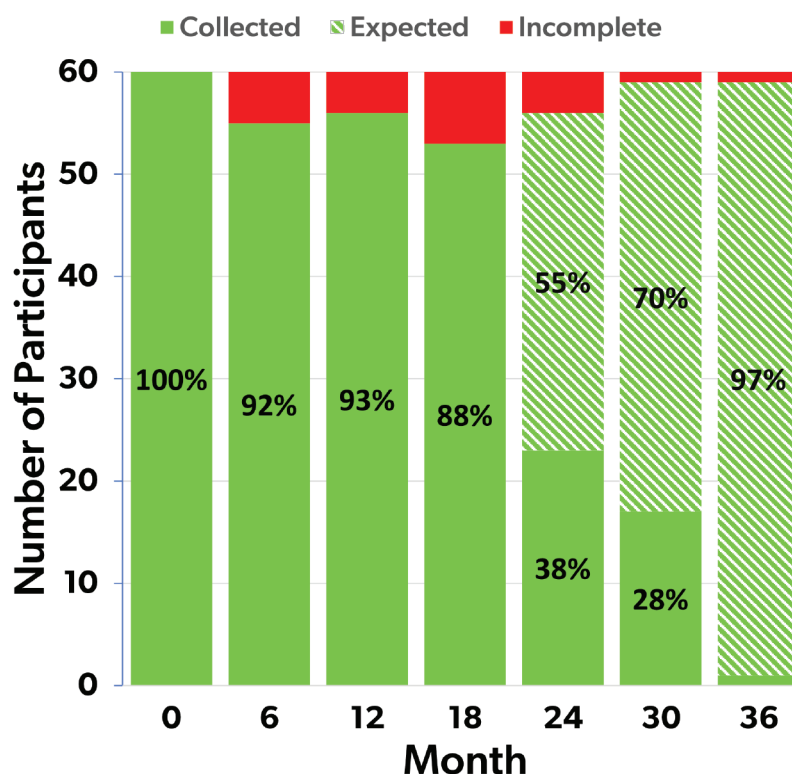
Special thanks to Nnaemezie (Nnanna) and Kevin for their assistance and support for study operations during staff transitions.

Data Collection is Going Strong

We are excited to report that we have completed data collection from baseline to 18-month with over 88% of you completing the online surveys!

Take a look at the graph on the right to see our progress. The “Expected” bars are future data collections.

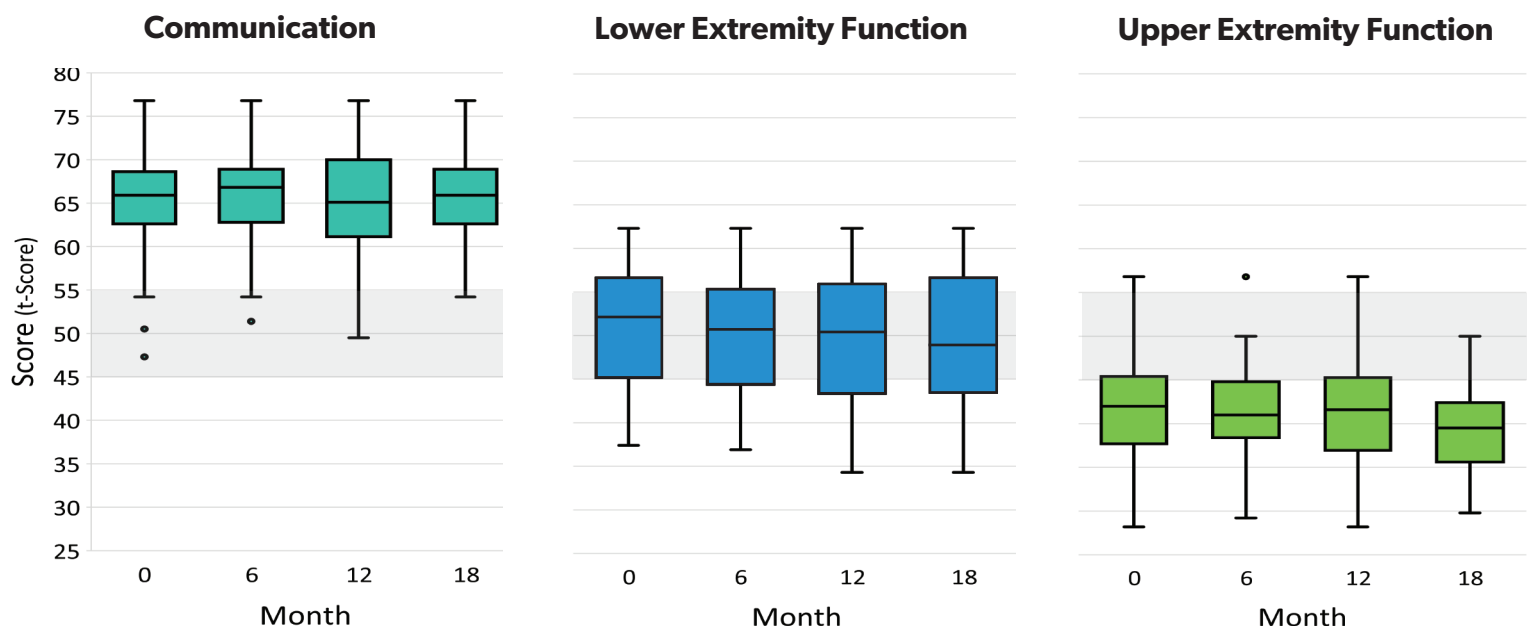
We will continue data collection for the next 18 months. Look out for emails from Paulo (Paco@sralab.org). Thank you for allowing us to stay in contact with you every six months for three years. We look forward to continuing to hear about your successes at work and to providing services to assist with employment challenges.



Preliminary Data Analysis

Our online surveys track your self-reported function, quality of life (QoL), and job satisfaction over time. In the future, we will examine relationships between these factors. However, we wanted to share a few interesting findings we have noted so far.

The three graphs below show the group’s self-reported communication, lower extremity function, and upper extremity function every 6 months. The shaded region (score 45-55) represents the average expected result for adults with neurologic conditions. The colored boxes inside the graph show the middle 50% of our group. As a group, there is good stability over time, with communication higher than average and upper extremity function lower than average.



Communication, lower extremity function, and upper extremity function are subscales of the Neuro-QoL™ assessment. Each subscale is scored from 0-100. A score of 50 is classified as average with higher scores indicating better than average.

Resources for Working with Parkinson's Disease

Some people with Parkinson's disease (PD) experience changes that impact their job performance related to their Parkinson's or other work demands. You may benefit from seeking help from a professional to help you address these challenges.

How could a neurologist help?

A Movement Disorders Neurologist is the best person to treat PD-specific problems.

Treat: Help manage PD symptoms such as tremor, anxiety, or mood

Refer: Provide referrals to see other specialists who could help with job-related issues

How could rehabilitation help?

Physical therapist (PT): Help with walking, balance, endurance, pain or stiffness

Occupational therapist (OT): Provide strategies for hand coordination for computer use, handwriting, energy conservation for fatigue, ergonomic advice for office setup

Speech Language Pathologist (SLP): Provide strategies to improve voice control for phone calls, public speaking, and concentration at work

Assistive Technology: Could work with an OT or SLP to learn about technology that can help with productivity in the workplace, including working from home

How could a social worker help?

Social workers have knowledge about supportive resources for people with PD.

Support: Help find community resources, discuss changes in the workplace, provide strategies for stress management

Educate: Share information about employment-related policies, problem-solve and make referrals regarding difficulties at work

Guide: Provide guidance on issues related to disclosing your diagnosis, Medicare, insurance, Social Security and Disability, and the Americans with Disabilities Act

How could vocational rehabilitation (VR) help?

A vocational rehabilitation (VR) counselor is different from an occupational therapist. A VR counselor has expertise in topics such as disclosing PD to an employer, helping to request the right accommodations, and discussing how to interview for new jobs.

Navigate: Help work through the decision to disclose PD status to an employer or colleagues, guide through job search, changing job roles, or returning to work, facilitate benefits or FMLA with employer

Accommodate: Recommend strategies to assist with organization and concentration, physical accessibility at work, transportation, or travel

If you have additional questions or concerns about employment:

For vocational rehabilitation: contact Paulo Aco at paco@srilab.org or (312) 238-7275

For social work: contact your neurologist's office for assistance